



Charcot-Marie-Tooth Disease: Newly Diagnosed

This fact sheet guides you through the beginning steps of what to do once you've received a diagnosis of CMT. It describes specialists who may be part of your health care team; how to find doctors and specialists; and what you can do to become an active participant in your long-term health care plan.

What types of doctors and specialists do I need to see?

You may not need to see all of the following doctors and specialists, but many might be involved in your care:

- ⌘ A family doctor or general practitioner treats all illnesses and may refer you to a specialist to help diagnose your condition.
- ⌘ A pediatrician treats infants, children, and adolescents and may refer your child to a specialist.
- ⌘ A neurologist specializes in nervous system diseases, including CMT; performs examinations and tests to diagnose CMT.
- ⌘ A podiatrist specializes in foot problems and diseases and can help you to develop a treatment plan; may refer you to an orthopedist.
- ⌘ An orthopedist specializes in problems related to the bones, joints, and muscles; can help with your treatment plan; may refer you to an orthotist for braces or other devices.
- ⌘ An orthotist designs and fits orthotics, such as leg braces, and will work with you to design and fit devices to correct bone and joint problems.
- ⌘ An orthopedic surgeon performs surgery involving the bones and muscles and can operate to prevent or correct deformities.
- ⌘ A physiatrist specializes in physical medicine and rehabilitation; can help with your treatment plan; may refer you to physical and occupational therapists.
- ⌘ Physical and occupational therapists work to increase muscle strength and restore movement and function; can help you to develop a strengthening plan.

- ⌘ Mental health specialists (such as therapists, psychologists, and psychiatrists) can provide support and help you to better cope with CMT.

How can I find a doctor or specialist?

It's important to try to work with doctors and specialists who are familiar with CMT. Not all of them are, so be sure to talk with them on the phone before your appointment to find out about their CMT experience. It's also important to work with a health care team that you are comfortable with and that you trust. You can always refer a trusted medical professional to the National CMT Resource Center, www.help4cmt.com, for information and training if he/she is unfamiliar with CMT. Finally, don't be afraid to ask for a second opinion or a referral to see a different specialist.

There are many ways to find doctors and specialists:

- ⌘ Talk with your general practitioner or family doctor for recommendations and referrals.
- ⌘ Check with your insurance company to find specialists.
- ⌘ Visit online CMT support groups for information about doctors in your area.
- ⌘ Visit or contact the National CMT Resource Center and other sites, such as MedlinePlus and university medical centers near you, to find a specialist.

What should I do to prepare for my appointments?

Appointments can be brief, so ask someone to come with you and take notes so that you can focus on the discussion. Write lists of the following:

- ⚡ Detailed descriptions of all your symptoms—printable checklist available on the National CMT Resource Center website
- ⚡ All of your medications and dosages, including nonprescription drugs and supplements
- ⚡ Any known or suspected family history of CMT
- ⚡ Questions for the doctor, such as what tests or treatments he or she may recommend

What can I expect from my doctor?

Your doctor is likely to ask you a number of questions. Being ready to answer them may allow for more time to focus on things important to you. Your doctor may ask:

- ⚡ Do you have any other health problems, such as diabetes or high blood pressure?
- ⚡ When did you first begin experiencing symptoms?
- ⚡ Do you have the symptoms all the time or occasionally, and how severe are they?
- ⚡ Does anything seem to improve your symptoms?
- ⚡ What, if anything, appears to worsen your symptoms?
- ⚡ Does anyone else in your family have CMT? Who and what type of CMT?

What questions should I ask my doctor?

Here is a list to get you started:

1. Do you have experience working with patients with CMT?
2. What type of CMT do I have, and what does that mean for me?
3. What is my outlook for the future?
4. What are my treatment options, and are there alternative therapies I can try?
5. How soon do I need to make any decisions about treatment?
6. Is there anything that I should avoid, such as certain medications or exercises?
7. Will I need any additional tests, and if so, what kind and when?
8. How often should I see you?
9. If my symptoms worsen, what should I do? When should I contact you?

10. Do the specialists you are referring me to have experience in treating people with CMT?
11. Now that I have this diagnosis, what changes will I need to make in my daily life?
12. What resources do you recommend for more information?
13. Is there information or training that my family/caregivers will need?

How can I become an informed patient?

Living with a progressive disease means becoming actively involved in your health care. In fact, people who understand and participate in their health care achieve better results than those who don't. These are some simple steps you can take:

- ⚡ Learn more about CMT from reliable and trusted online sources.
- ⚡ Keep copies of your medical records.
- ⚡ Understand your health insurance policy.
- ⚡ Develop a good support system.
- ⚡ Develop trusting relationships with your health care team.
- ⚡ Work with your health care team to decide on a treatment plan that works best for you.
- ⚡ Continue to reevaluate your plan with your health care team as your health changes.